



UNDERSTANDING CHRONIC, COMPLEX, AND RARE CONDITIONS AS A POLICYMAKER



As policymakers, a deep understanding of chronic, complex, and rare conditions is crucial for developing effective health policies and creating a more equitable healthcare system. By learning about these conditions, you can make informed decisions that improve patient outcomes, allocate resources effectively, and advocate for necessary changes in healthcare legislation. Your role in shaping health policy can lead to meaningful improvements in the lives of individuals affected by these conditions and foster a healthcare environment that supports diverse patient needs.

Understanding these conditions helps you create policies that address gaps in healthcare, promote equitable access to care, and support advancements in treatment and research. Your insights into these conditions can lead to better-informed policy decisions, improved healthcare programs, and increased support for both patients and healthcare providers.

CHRONIC CONDITIONS

Definition: Chronic conditions are long-lasting diseases or health issues that persist for three months or more and may worsen over time. Common examples include diabetes, heart disease, and arthritis. These conditions require ongoing management and significantly impact daily life.

Impact: Chronic conditions affect millions of people worldwide, requiring long-term management and presenting significant challenges for individuals, families, and healthcare systems.

Management and Challenges: Managing chronic conditions often involves a multidisciplinary approach, including medications, physical therapy, and lifestyle changes. Patients face both physical symptoms and emotional, financial, and social challenges.



STATISTICS:

- **60% Of Adults In The U.S. Have At Least One Chronic Condition With 40% Having Two Or More Chronic Conditions**
- **70% Of All Deaths In The United States Are Due To Chronic Disease, Making It The Leading Cause Of Death And Disability**
- **66% Of U.S. Physicians Reported That Their Training Did Not Adequately Prepare Them To Educate Patients With Chronic Diseases**
- **8 Million More People Are Being Diagnosed With Chronic Diseases Every Five Years, Contributing To A Steady Rise In Prevalence In The United States Over The Last 20 Years**
- **86% Of Health Care Costs Are Attributable To Chronic Disease**
- **34% Of Chronically Ill Respondents Reported In A Study As Being Treated As Unreliable Sources Of Their Symptoms During Clinical Encounters, Often Experiencing Their Illness As Dismissed Or Invalidated**
- **80% Of Those Affected By Autoimmune Diseases Are Women, Who Also Face A Disproportionately High Morbidity From These Conditions, Despite Them Not Being Female-Specific**
- **53% Of Adults Aged 18—34 Years Have At Least One Chronic Condition, And 22.3% Have More Than One Condition**
- **64% Of US physicians Reported That Their Training Did Not Adequately Prepare Them To Manage The Psychological And Social Aspects Of Chronic Disease Care**
- **39% Of Chronically Ill Respondents In A Study Cited Their Doctor's Gaslighting As A Reason For Delays In Medical Care And Lengthy Diagnostic Journeys**

COMPLEX CONDITIONS

Definition: Complex conditions are chronic conditions that affect multiple body systems and often require extensive care over a long period of time. Examples include cystic fibrosis, multiple sclerosis, and certain types of cancer.

Impact: These conditions are characterized by their multifaceted nature, involving multiple symptoms or complications. They often require comprehensive care and can significantly impact physical, mental, and emotional well-being.



Management and Challenges: Managing complex conditions involves a coordinated approach with various specialists. The healthcare system faces challenges in providing consistent, high-quality care, and patients often deal with high medical costs and complex treatment plans.

- **27% Of Adults In The United States Have Multiple Chronic Conditions**
- **89% Of Patients In A Study Of Those With A Complex Condition Reported they experienced a dismissive attitude from their health care provider**
- **71% Of Patients Had To See Four Or More Physicians Before Receiving An Accurate Diagnosis For Their Complex Disease**
- **17% Complex Disease Patients Reported Their Physician Displayed A Lack Of Knowledge About Their Condition**
- **57% Of Complex Condition Patients Reported Being Treated Poorly By Their Doctors**
- **\$15,000+/- More Is Spent Per Year On Healthcare By Those With Complex Conditions Compared To Those With Less Complex Conditions**
- **42% Of People In America Have 2 Or More Chronic Conditions, And 12% Have At Least 5**
- **77% Of Chronically Ill Patients In A Study Reported Having Negative Interactions With Healthcare Professionals**
- **24% Of Women Report Multiple Chronic Conditions, Compared To 25.9% Of Men**
- **55% Of Patients With Complex Diseases Are On Multiple Medications, Often Leading To Medication Management Issues And Potential Drug Interactions**

RARE CONDITIONS

Definition: Rare diseases affect fewer than 200,000 people in the U.S. Examples include Huntington’s disease, Gaucher disease, and muscular dystrophy.

Impact: Despite their rarity, these conditions collectively affect a substantial number of people. They often lead to significant health problems, delayed diagnoses, and limited treatment options.

Management and Challenges: Managing rare diseases involves navigating a “diagnostic odyssey” and accessing experimental treatments. Rare diseases often lack adequate resources and support networks.



STATISTICS:

- **30 Million People In The United States, Equating To About 1 In 10 Americans Are Diagnosed With A Rare Disease**
- **5 Years On Average For Patients With Rare Diseases To Receive An Accurate Diagnosis, But It's Not Uncommon For This Process To Take Anywhere From 5 To 30 Years**
- **7,000 Distinct Rare Diseases Are Currently Identified Worldwide**
- **5% Of Rare Diseases Have FDA-Approved Treatments, Highlighting A Significant Gap In Available Medical Therapies**
- **40% Of Cases Involving Rare Diseases Have Diagnostic Errors, Leading To Delays In Appropriate Treatment And Management**
- **95% Of Rare Diseases Lack An Approved Treatment, Leaving Patients To Navigate A Healthcare Landscape Where Options Are Limited And Often Experimental**
- **75% Of Orphan Drugs Are Only Approved For A Single Rare Disease**
- **50% Of The National Hospital Healthcare Bill Is Spent On Treating Rare Diseases, Even Though they affect less than 10% of the U.S. population**
- **50% Of Patients And Caregivers Attributed Diagnostic Delays To A Lack Of Disease Awareness, While 42% Cited Limited Medical Specialization As A Cause**
- **17% Of Patients Reported Having To Relocate Or Are Considering Relocating To Access Care For Their Rare Disease**

SIMILARITIES BETWEEN CHRONIC, COMPLEX, AND RARE CONDITIONS

Understanding the similarities between chronic, complex, and rare conditions helps to create a unified approach to advocacy and support. All three types of conditions require long-term management and significantly impact the quality of life for patients. They each involve high healthcare costs, frequent medical visits, and a need for specialized care. Additionally, patients often face emotional and psychological challenges and must advocate for their needs within the healthcare system.



Similarities:

- **Long-Term Management:** All three types of conditions require ongoing management over extended periods, often for a lifetime.
- **Impact on Quality of Life:** These conditions significantly affect daily lives, impacting physical, emotional, and social well-being.
- **Need for Specialized Care:** Patients often require care from specialists with expertise in their specific conditions.
- **Frequent Medical Visits:** Individuals typically have frequent appointments with healthcare providers to manage symptoms and monitor progress.
- **High Healthcare Costs:** Managing these conditions leads to substantial medical expenses.
- **Care Coordination:** Effective management requires coordination among multiple healthcare providers.
- **Importance of Patient Advocacy:** Patients must advocate for themselves to receive appropriate care.
- **Emotional and Psychological Support:** These conditions often necessitate mental health support.
- **Potential for Misdiagnosis:** Patients are at a higher risk of misdiagnosis or delayed diagnosis.
- **Need for Tailored Treatment Plans:** Each patient's treatment plan must be customized.
- **Support Networks:** Patients benefit from support groups and networks.
- **Research and Advocacy Needs:** Ongoing research and advocacy are crucial for improving treatments and patient outcomes.

DIFFERENCES BETWEEN CHRONIC, COMPLEX, AND RARE CONDITIONS

While chronic, complex, and rare conditions share some common challenges, they also have distinct characteristics that require targeted approaches. Understanding these differences helps in crafting effective advocacy strategies and addressing specific needs.

Differences:

- **Prevalence:** Chronic conditions are widespread, complex conditions are less common, and rare conditions affect fewer people.
- **Diagnostic Challenges:** Chronic conditions have established diagnostic criteria, complex conditions require multiple tests, and rare conditions often face significant diagnostic hurdles.
- **Treatment Availability:** Chronic conditions have established treatments, complex conditions require multifaceted care, and rare conditions often lack approved therapies.
- **Public Awareness:** Chronic conditions are widely recognized, complex conditions are less known, and rare conditions suffer from low awareness.
- **Research Funding:** Chronic conditions receive substantial funding, complex conditions receive moderate funding, and rare conditions struggle for adequate research support.
- **Healthcare Provider Expertise:** Chronic conditions are managed by many providers, complex conditions require specialists, and rare conditions have the fewest knowledgeable providers.
- **Symptom Complexity:** Chronic conditions affect one or two systems, complex conditions affect multiple systems, and rare conditions have varied symptoms.



UNDERSTANDING CONDITION CATEGORIES

Understanding the differences and similarities between chronic, complex, and rare conditions is not just about medical knowledge; it's also about shaping effective health policies and advocating for systemic changes. Each condition category has distinct needs and challenges, which must be considered when creating policies that support patients and the healthcare system as a whole.

Key Points to Understand:

- Chronic Conditions require policies for long-term management and patient support.
- Complex Conditions involve policy considerations for multidisciplinary care and coordination.
- Rare Conditions need policies for research funding, diagnostic support, and access to treatments.

By recognizing these distinctions, you can craft policies that are comprehensive, equitable, and responsive to the needs of all patients. Your role as a policymaker involves not only addressing immediate concerns but also fostering a healthcare environment that supports ongoing research, effective treatments, and compassionate care.

HOW RISE & RALLY CAN HELP

Rise & Rally offers support to policymakers through advocacy efforts, policy recommendations, and public awareness campaigns. We can provide expertise and resources to help you understand these conditions and develop effective health policies.

Policy Development Support: Work with us to develop policies that address the needs of patients with chronic, complex, and rare conditions. We offer guidance on crafting legislation, creating initiatives, and evaluating policy impacts.

Advocacy Opportunities: Engage with us for opportunities to advocate for systemic changes that benefit patients. We offer resources for effective advocacy, from drafting policy proposals to mobilizing community support.

Educational Resources: Explore our resources for additional information on these conditions and their impact. We are here to assist you in making informed policy decisions and supporting your advocacy efforts.

THANK YOU FOR WHAT YOU DO!

For more resources, guides, and opportunities to connect with others who share your passion for advocacy, please visit our website at www.riseandrally.org and follow us on Instagram at [@riseandrally_](https://www.instagram.com/riseandrally_)